

BONE CANCER RESEARCH TRUST

MINUTES OF MEETING HELD ON SUNDAY 15TH JULY 2007 AT THE LEICESTER HILTON HOTEL FOLLOWING THE FIRST BCRT CONFERENCE THE PREVIOUS DAY.

1. PRESENT

Trustees:- Mike Francis, Ian Lewis, Gill Pilcher, Nick Bones, Patrick Hardman, John Dealey, Patricia Smith.

Officers :- Ros Francis, Alan Johnson, Kate Connor.

Visits from:- Marian Dealey, Chris Smith, Ken Allbon, Claire Hardman, Chris Wickham, Fiona Foley, Ciara Hoolahan, Ffion Miles.

APOLOGIES

Trustees:- Rob Grimer, Debbie McCartney, Gill Callar.

2. MINUTES

Minutes of the Meeting of Trustees held on 26th May 2007 were agreed and signed.

3. MATTERS ARISING

Matters not covered by later Agenda items:-

3.1 Follow-up from the Conference for Professionals held at the Belfry Hotel on 26th, 27th March 2007.

- A short report (two sides of A4) had been written by Lee Jeys (Surgical Registrar at the Royal Orthopaedic Hospital, Birmingham) who also played a large part in the organisation of the Conference. This report had been displayed for information for delegates at the BCRT Patients' and Supporters' Conference and will be put on the website.
- Ian Lewis reported that he had given presentations on the Conference to the Royal College of Paediatrics, to the Euro Ewings Group in Newcastle and the CCSG in Dublin. Lee Jeys had spoken to the Orthopaedic Association.
- The data, including the results of the electronic recording of delegates' votes concerning the management of case studies discussed during the Conference, is still being analysed and will eventually be published.
- Lee Jeys to carry out the writing up of the findings. BCRT Trustees agreed to fund the time for him to do this if necessary, to ensure the maximum benefit from the Conference.

3.2 The meeting between John Dealey and Emma Upton in London.

Emma Upton and Katie Emmitt are to raise funds for BCRT through a 10 day sponsored trek in Peru and wanted to meet someone from the charity. John was pleased to meet them and was impressed by their enthusiasm.

- It was noted by Trustees that when supporters are attempting substantial fund raising events with a high entry fee, such as this, then the amount should be paid up front as this is safer for the charity, should further funds not be raised for any reason.

3.0 MATTERS ARISING continued:-

3.3 Fiona Foley joined the meeting to discuss future contributions from her fund in Ireland. The Trustees expressed their gratitude for the €25,000 (approx £16,500) recently received.

Fiona was pleased that Ian Lewis had been able to visit to meet some of trustees of her charity. There was discussion on ways of maintaining a flow of information about BCRT with them, especially around current and prospective research. Arrangements for dedicated funds in memory of a named person were explained.

3.4 Ciara Hoolahan joined the meeting. Trustees expressed their gratitude for her brave contribution to the Conference through sharing her personal story.

3.5 Ffion Miles joined the meeting. Trustees had been very pleased to meet her and for her input to the Conference in maintaining contact with the Childhood Eye Cancer Trust (CHECT) and BCRT, having the link between Retinoblastoma and Osteosarcoma.

3.6 Funds from Patricia Smith. Trustees were grateful to receive a cheque for a further £4,000 that Patricia had collected in Ireland.

- There was some discussion about ways of getting the best exchange rate for the conversion from euros.

ACTION - Kate

4. CORRESPONDENCE – None.

5. FINANCE

5.1 Statement of Accounts.

- Statements were presented for the main account and for the four dedicated accounts, the total amount to 13.07.07, with £20,795.80 to be paid in, standing at £376,630.85. All Trustees agreed that the accounts be accepted.
- It was decided that financial information should be circulated prior to the meeting with the Agenda, in future.

5.2 Approval of Expenditure.

- Merchandise. As agreed at the last meeting, a range of merchandise had been purchased including t-shirts, sweatshirts, badges, collecting cans and Christmas cards. Information about purchasing these was now on the website. Including books that had been kindly donated from Andrew Belshaw and from Marc Woods, income from the sale of all these items had amounted to £450 during the Patients' and Supporters' Conference.

5.2 continued

- Patients' and Supporters' Conference. Expenditure for the Conference had totalled £4,443.05 with postage, printing etc. to be added. Trustees expressed their gratitude to Cambridge Laboratories for their sponsorship of £5,000. A letter of thanks with information on the results and benefits of the Conference to be sent.

ACTION - Mike

5.3 Charity Commissioners. It was reported that they will soon be requesting BCRT's accounts from the first three months (to 30th June 2006). This full year's accounts (2006-2007) about to go to the Auditors.

Ideas being considered of ways to represent the accounts graphically and clearly on the website.

ACTION – Mike, Kate and all.

5.4 A Financial Plan.

- This will be required to be sent with the audited accounts to the Charity Commissioners. It needs to clearly show the monies committed to research.
- It was felt that BCRT should begin to invest, starting conservatively, to make more of the money now sitting in the accounts. Financial advice needed, information to be gathered for the next meeting. **ACTION – Mike, Gill, Kate.**

6. SCIENTIFIC ADVISORY PANEL

6.1 Decisions on the second round of Research Grant applications.

- Ian Lewis reported that there had been 5 applications, asking for around £30,000 each. These applications had been put out to 13 external reviewers and Ian reminded Trustees of the scoring system used. The results of these had then been studied by Ian Lewis, Rob Grimer and Jeremy Whelan who felt that 4 of the 5 were worthy of serious consideration. Ian suggested that the Trustees might need to decide how much they should commit to research during this second year on small projects bearing in mind that there could be a situation later when they might want to commit a large amount to one big piece of research.
- Following discussion, the Trustees formally approved one application and identified two others which would be approved subject to satisfactory responses to requests for further clarification. Two applications were deemed unsatisfactory and would be given feedback.

6.2 The third round of grant applications.

Closing date to be 22nd October 2007.

Notification of the outcome to be at the end of January / beginning of February 2008.

7. PATIENTS' AND SUPPORTERS' CONFERENCE

Held on Saturday 14th July 2007 at the Hilton Leicester Hotel.

As the Conference had only been held the day before, the following are the immediate thoughts and comments of the Trustees. The whole event will be looked at in more detail at the next meeting.

- All were delighted with the way the day had gone. It had engendered comradeship around a common situation which included much emotion and admiration.
- The prior publicity and the event itself had greatly raised the profile of BCRT amongst both professionals and lay people. It had shown professionalism and had a high level of credibility.
- There had been a wide range of people attending.
- Trustees had been delighted to meet Iris Arrowsmith who visited especially to present a cheque for £40,000 raised in memory of her son Matthew.
- Delegates' individual evaluations to be collated and studied – some still to come in.

ACTION - Kate

- What would we need to consider doing differently or to add at a future conference? :-
time, as expected, had been an issue with so much to fit in;
be sure of topics that delegates want to hear and that reflect the work of the charity;
preparation of speakers for the type of audience ie. the delivery, pace and vocabulary of the two doctors from Birmingham had been hard to follow although the content was appropriate and interesting.
- Feedback from the two sessions of discussion groups will be typed up ready for discussion at the next meeting. **ACTION - Kate**
Points already mentioned were:-
 - to enable some sort of networking between the authors of the stories on the website;
 - to be able to give more support with advice on benefits etc;
 - to be able to give and receive (non medical) support by phone.
- Mike reported that he had asked Marc Woods to be a patron of BCRT and he had accepted.
- Thanks were recorded to Kate Connor (Administrator) for all that she had done in preparation for the Conference.

8. WEB-SITE MANAGEMENT

There was much discussion around the presentation of the Stories. Now that there are so many, it was felt necessary to categorise them in some way so that readers could easily find others with aspects in common with themselves ie:-

Patient Stories Family Stories Osteosarcoma / Ewings Amputation / Prosthesis

Alan Johnson (Website Manager), felt this would be possible and agreed to experiment with the idea. **ACTION – Alan**

9. MARKETING, PUBLICITY AND FUND-RAISING

9.1 The Leeds Run For All had taken place successfully with 56 runners for BCRT. The target of raising £10,000 had been exceeded. Runners had appreciated a venue enabling them to meet together afterwards. The aim is to have 150 runners next year and some have signed up already! Grateful thanks recorded to Kate Connor for organising BCRT's part in the event, also to Nick Bones and Marc Woods for the publicity they were able to give BCRT via television and radio.

9.2 A Professional Fund-Raiser. Ian Lewis reported that he has made progress with preparing a job description and is continuing to endeavour to find an office for BCRT.

9.3 Merchandise.

- Kate Connor reported that she had added sweatshirts with hoods to the range of merchandise to cater for a different age group.
- Gill Picher ensured that all Trustees had taken their allocation of Christmas cards to sell.

11. REVIEW OF TRUSTEES' MEMBERSHIP

This became a wider discussion, not just about the appointment of trustees but also about the practicalities of travel and time for meetings and of keeping all interested people informed of BCRT's progress.

- **Trustees.** Consideration of the current situation continued. It was felt necessary to prepare for a time when there may be a change in the current combination of trustees or others with particular skills may be added. These could perhaps be in publicity, investment or legal matters. Three names were suggested.
- **Titles.** There was discussion around a range of people's involvement with BCRT and the names and positions they may have in the charity's structure. Names such as "associates", "affiliates", "Board of Trustees", "National Committee", "patrons", "supporters" were suggested.
- **Dissemination of Information** The idea of producing a BCRT newsletter was again discussed. Enthusiasm for this continued with thoughts of content and an idea of a possible editor to be approached. This would help to keep a wider range of interested people informed of all that is happening within BCRT.

12. ANY OTHER BUSINESS - None.